OUTLOOK EXTRA

IVIG: A patient's guide

The immune system

If you have an autoimmune disease, your immune system fails to distinguish between yourself and harmful invaders, and produces autoantibodies. These antibodies "attack" and damage different body systems. In myositis, they attack the muscle, but there are other targets in other autoimmune disease. For instance, in Guillain-Barre Syndrome and myasthenia gravis, they attack the peripheral nervous system.

IVIG is an immunomodulator, which means it adjusts (or moderates) the level of an immune response. Scientists don't know the exact mechanism of action for IVIG in autoimmune disease, but there are many theories as to how IVIG provides this immunomodulatory effect.

In patients with autoimmune diseases, or other conditions where the body's immune system is not functioning as it should, IVIG can help regulate an overactive immune system by signaling it to slow down or stop inflammatory processes. It has also been hypothesized that IVIG might redirect the out-of-control immune system from the body's tissues by serving as a target for the auto-antibodies, acting as a kind of decoy target. Thus it diverts the abnormal immune system from the body's normal organs. Or it may provide antibodies (presumably lacking in the patient) that are present in the blood of the larger pool of normal donors. Whichever theory is correct, it is now documented and well accepted that IVIG does work. For many patients, IVIG is the safest and most easily tolerated treatment available. IVIG has significantly improved the quality of life for many myositis patients. Unlike prednisone and all other drugs prescribed for myositis, IVIG does not negatively impact the immune system.

The making of a natural product

Gammaglobulin is an immunoglobulin — an antibody — produced by Bcells, a type of white blood cell. Immunoglobulins kill viruses, bacteria, and types of fungus and parasites. These antibodies are blood proteins in the immune system. The antibody used in IVIG comes from plasma, which is the liquid part of blood. Immunoglobulins are found in human plasma collected from many thousands of donors, whose blood is then pooled.

To ensure the safety of IVIG in the United States, the source plasma for IVIG must be from one of the nearly 400 FDA-licensed plasma donation centers in this country. This is true even if the IVIG is actually formulated outside the U.S.

Each of the FDA-licensed donation centers is required to comply with strict quality standards. Plasma and plasma donors are required to undergo a number of rigorous procedures. These safeguards are:

• Potential donors must pass two separate medical screenings. Donors are tested for HIV, hepatitis B and hepatitis C on two different occasions. Only after two satisfactory screenings and negative test results can a person become a qualified donor. If a donor does not return within six months, he or she must qualify by completing the same tests again.

• Viral markers measure the number of positive test results each center receives each month. The results are reported and compared to a national standard to assess the safety of the donors and the collective safety of each center.

■ There is an inventory hold requirement for each plasma donation. Each donation is held for at least 60 days before it may be used for producing IVIG.

■ The use of Nucleic Acid Amplification Technology screening uses state-of-the-art technology to allow for the earliest possible detection of transmissible disease.

All plasma that is used for therapeutic purposes also is tested for Parvovirus B19, a common infection that often has no symptoms.

These requirements ensure that IVIG products made in other countries are just as safe and effective as those made in the United States. There have been no documented cases of HIV or hepatitis since the start of IVIG therapy because of the above steps.

Kinds of immunoglobulins

■ IgG – This is the most common immunoglobulin in blood, accounting for 75 percent of the immunoglobulins available. It coats microbes, speeding their uptake by other cells in the immune system. It also crosses the placenta and confers immunity to newborns. ■ IgA – This is the second most common, and concentrates in body fluids like tears, saliva, respiratory and digestive secretions. IgA plays a role in local immunity.

■ IgM – The third most common immunoglobulin in serum, is effective at killing bacteria. IgM is the first immunoglobulin produced by B cells in response to antigens.

■ IgE is the least common immunoglobulin in blood. It protects against parasitic infections, binds to basophils and mast cells and is involved in allergic reactions.

■ IgD remains attached to B cells and functions as a receptor for an antigen.

IVIG treatment

IVIG therapy is given intravenously (administered into a vein.) A nurse inserts a small tube with a needle into a vein on the hand or arm. The infusion is started slowly and is increased slowly until the appropriate rate is achieved. While giving the infusion, the infusion nurse carefully watches vital signs, including blood pressure, pulse and temperature.

The length of time it takes for an IVIG infusion will vary for each person. On average, it is between four to six hours. The specific dose ordered by the physician, in addition to the patient's own tolerance for the medication, will determine the length of the infusion.

Generally, IVIG therapy is administered for at least six months to allow the physician to assess its benefit. Deciding whether it should continue is a decision best made jointly by the patient and the physician.

There are some side effects possible with IVIG therapy, but side effects are most often related to the rate of the infusion, rather than the product itself. In most cases, the treatment continues and adjustments are made before the next infusion to prevent side effects, most commonly by decreasing the rate, administering extra fluids along with the IVIG, or offering medication to the patient before or after.

The most common side effects are head, stomach or back pains, and most can be controlled with over-thecounter anti-inflammatory and antiallergy medications like acetaminophen (Tylenol) and antihistamines (Benadryl).

Less common side effects are allergic reactions: wheezing, chest pain, difficulty breathing, hives, low blood pressure and rapid heart rate. These are treated with antihistamines, epinephrine, fluids and steroids. IVIG is not used in patients who have a history of anaphylactic or severe systemic reaction to immunoglobulin, and patients with IgA antibodies.

IVIG therapy is safe for pregnant women and, since pregnancy and childbirth are sometimes factors in autoimmune diseases, women sometimes receive IVIG after delivery to guard against a relapse.

INSIGHTS Study

A study examining quality and consistency in prescribing IVIG for myositis patients is presently underway by NuFACTOR Specialty Pharmacy. It is part of a larger study looking at a number of diseases for which IVIG is prescribed, none of which presently have prescribing guidelines. TMA Medical Advisory Board Member Todd Levine is the lead researcher for the project, called the INSIGHTS study.

The study will examine the outcomes of prescribing regimens in NuFACTOR patients, and be reviewed by experienced clinicians, with the goal of developing evidence-based clinical guidelines for IVIG treatment.

Getting ready for an infusion

Any patient preparing for IVIG therapy should be sure to drink plenty of fluids, increasing the normal amount of fluids they drink on the day before and the day of the infusion. Drinks with caffeine, like coffee, tea and colas should be avoided, since caffeine acts to flush fluids from the body.

Review of IVIG and myositis

Physicians treating patients with dermatomyositis and polymyositis have traditionally started treatment with IVIG when the most common medications -- steroids -- do not seem to produce an adequate response to induce remission of disease; or where the disease is rapidly progressive, with severe weakness; or when steroids produce side effects that are unacceptable.

In these circumstances, IVIG is the preferred agent of choice, according to a number of studies, reviewed by Dr. Marinos Dalakas in 2010, including a double-blind, placebo-controlled study. In some of these cases, Dr. Dalakas said, after initiating the recommended starting dose, the improvement in strength can be impressive and becomes noticeable even as soon as 15 days after the first infusion.

Repeated infusions after a certain interval (regimens specify anywhere from four to eight weeks) might be required to maintain the response. In children or patients with diabetes (which is aggravated by steroid treatment) IVIG is sometimes used soon after the initiation of steroid therapy, to immediately reduce the amount of prednisone needed.

In several open-label trials included in the Dalakas review, IVIG was shown to be effective for a majority of patients with polymyositis and dermatomyositis.

Recently, the American Academy of Neurologists (AAN) issued guidelines for physicians and patients about how IVIG works for treating certain neuromuscular disorders. Neurologists from the AAN are doctors who identify and treat diseases of the brain and nervous system. The guidelines followed a study by experts who carefully reviewed all available scientific studies on use of IVIg for treating certain disorders of the nerve and muscle.

In the guidelines, researchers found evidence that IVIG was effective in treating dermatomyositis; and called for more research on the role of IVIG in treating polymyositis.

In juvenile dermatomyositis, IVIG has been used successfully to enable physicians to lower prednisone dosage, which has side effects that are particularly troublesome in young patients. A retrospective review of 78 patients at the Hospital for Sick Children in Toronto, showed that those receiving IVIG (because of the severity of their disease at diagnosis, because of their poor response to steroids, or because of their dependence on long-term steroids) showed lower disease activity, less likelihood of relapse and better health-related quality of life than children who did not receive IVIG.

Home infusion

Home infusion therapy is the administration of IVIG at home. The most common diseases for which drug therapies are administered at home are those that require long-term or lifelong medication. Home infusion is more cost-effective than an in-patient hospital stay. Most physicians also strive to decrease the exposure of immuno-compromised patients to hospitals, a measure that reduces the risk of opportunistic infection.

Remaining in your home with your family can promote quicker symptom relief and improve the quality of life for both patient and family or caregiver. Most patients like receiving IVIG therapy in the privacy and comfort of their own home and around their own schedules.

Home infusion therapy is arranged through a prescription and a referral from the patient's treating physician. Patients are carefully screened to determine if home administration is safe and appropriate for their individual needs. A registered nurse monitors all home treatments continuously. In new IVIG patients, the physician may require that the first dose be given in a controlled setting in case of any side effects, and he or she may also ask that all subsequent doses be done at home.

IVIG at home: one patient's story

Like many people with dermatomyositis, Angela Anderson first thought she was just tired. Anderson, a 53-year-old emergency medicine physician, worked grueling hours in the emergency department of a Rhode Island children's hospital. "Naturally, we were all worn out," she said. "Emergency medicine is just like that - you run around for ten hours without a break."

The red patches around her eyes and on her cheeks she attributed to a recent skiing trip (one where, she recalled later, she fell down a lot and had trouble getting up): "Not that it was so recent," she said. "Months passed, and I was still sunburnt."

But clearly, things had changed. Anderson couldn't raise her arms above her head and found she was reluctant to pick up babies because she was afraid of dropping them. "I'd move them around on the gurneys," she said. She also had trouble rolling over in bed and found her voice was becoming hoarse.

"It's funny how your mind works," she said. "I became convinced that no one my age could lift their arms very high." One day, she asked a room full of colleagues if any of them could raise their arms above their heads. One by one, all the arms went up.

When she visited a friend -- also a physician -- who was lifting her three year-old up in the air, Anderson mentioned that even picking the child up would be impossible for her. Concerned, the friend emailed another doctor with the words: "Something is terribly wrong with Andy." That Monday, the physician saw her and recorded a CPK count of more than 8,200. Anderson went on to work, but by that time, had a hard time even getting out of a chair. Her physician made a preliminary diagnosis of either DM or PM, and referred Anderson to a rheumatologist. "It was funny," Anderson said. "He told me that if I had a "V"-shaped rash on my chest, he would have diagnosed DM for sure. That night, sure enough, I stepped out of the shower and saw the rash clearly in my bathroom mirror."

The rheumatologist confirmed the diagnosis of DM by biopsy. "I was outrageously lucky to be diagnosed so quickly," Anderson said. She was not so lucky in the failure of the conventional treatment to control her symptoms. "I fought the treatment all the way," Anderson said. "I didn't want to be on steroids; I didn't want to be on Immuran, but what could I do? I could barely move."

She had to take a leave of absence from work, except for four hours a week where she helped out with pediatric pain and palliative care: "The emergency department was just too active, but in my new job, I could do a lot on the phone," she said. Otherwise, her life was pretty limited. "I could roll over in bed and swallow a little better," she said, "but I couldn't do much, in spite of the medication. A good day would be when I could go to the grocery store."

She visited TMA medical advisory board member Dr. Lisa Christopher-Stine, who co-directs the Myositis Clinic at Johns-Hopkins. Dr. Christopher-Stine, seeing that the steroids weren't very effective, urged her to try IVIG. "Just what I didn't want," Anderson noted. "More treatment, and I especially didn't want any blood products." She remained exhausted, convinced herself she had just gotten lazy, and went on for a couple of years without much change. "I have to say, it wasn't as bad as it was without treatment. But I just couldn't see the light at the end of the tunnel."

Finally, after a second visit to Johns-Hopkins -- "I literally cried in Dr. Christopher-Stine's office" -- she was encouraged again to at least try IVIG. Finally, she agreed.

"From then on, everything was taken care of," she recalled. "The clinic arranged the insurance. The nurse called me to set up the appointments for the week, and everything arrived at my house the day before: the pre-medication, the IVIG, the equipment, even the IV pole."

After five days of four-hour infusions, she didn't see much of a change, just fatigue on the first and second day and a headache on the third day. "The nurse and I just hung out and watched cooking shows," she said. Discouraged, she waited to see what the second course of infusion would bring the following month.

Once again, everything arrived at her house right before the nurse came to monitor the infusion. Once again, she felt extra tired for a couple of days and had a headache on the third day. "I was just about to call Dr. Christopher-Stine and say, 'let's stop this,' when I began to get much stronger. It happened pretty suddenly. I could play the piano, I could work for hours at a time, I could walk farther, I could even think more clearly."

About to have her third round of infusions, Anderson and the infusion nurse have worked out a schedule that minimizes the headaches and works with Anderson's new work schedule. She's been able to return half-time to her work at the children's hospital and has the infusions start on a Thursday evening: "That way, I can work all day, then take Friday off, and by Monday I am back to normal. I've found that, with home infusion, you can work around your schedule."

Anderson said she's now "not quite 100 percent, but so much better than before." She's down to just 1 gram of prednisone every other day and finds her strength still increasing. That's the biggest part of her successful treatment. But another part of her success with IVIG, she said, was the smooth way everything worked. "When you're so tired and weak, it's hard for you to make things happen. There were days when I wouldn't have had the energy to fill the prescription for the infusion, or gather up the pre-medication I needed, or get to the hospital for several hours. This has been perfect for me."

Resources for IVIG home infusion

It is often difficult for patients to navigate the issue of insurance coverage for IVIG. Treatments are very expensive, and many of the medical conditions for which IVIG is prescribed have not been approved by the Food and Drug Administration.

When prescribed for these conditions, IVIG is considered an "offlabel" use.

Off-label uses are supported by medical studies -- for myositis, most recently the study cited in the recommendation of the American Academy of Neurology -- but manufacturers have not conducted the large-scale clinical trials necessary for FDA approval. It is important to know that an off-label use does not prevent the treatment from being covered by most health plans, but the treatment must be authorized in advance.

A specialty pharmacy is often asked to provide additional and often detailed justification for the treatment. Home infusion providers can often provide resources for patients having questions about insurance coverage, and the following providers have patient assistance programs in place. They will also be able to help you find resources from IVIG manufacturers, many of whom also have patient assistance programs.

Walgreens

Walgreens offers a large nationwide nursing network, staffed by registered nurses specializing in complex therapies to keep plan management simple and flexible. There is a program that offers patients help with understanding insurance and billing across medical and pharmacy benefits, depending on the needs of the patient, Including assistance with custom infusion benefit design, patient assistance, and a single fee schedule for easy administration. Call 877-974-4844.

IgG America

IgG America has extensive experience working with health plans and insurance companies to make sure patients completely understand their health coverage for IVIG therapy before providing any treatment. They have specialists available to answer any questions regarding insurance and reimbursement. To contact the reimbursement department, call the office tollfree at 877-674-9700, or email reimbursement@iggamerica.com.

AxelaCare

AxelaCare offers home infusion patients initial and ongoing insurance authorization as well as reimbursement assistance throughout the course of therapy. Specialists review all available coverage, plan limits, and billing processes with your insurance carrier. They also provide a dedicated AxelaCare "Coach" for reimbursement, pharmacy and nursing support, and work with you on customized payment terms. Call 877-607-9352.

KabaFusion

KabaFusion has a complete team of insurance experts to answer your questions regarding insurance coverage for home infusion, and IVIG, with long-time experience dealing with Medicare, Part D plans, Tricare, Medi-Cal/Medicaid, as well as private insurance companies. For assistance call 1-877-577-IVIG (4844)

Note: Other home infusion companies also offer patient assistance.



JM COMPANION

For children, families and friends affected by juvenile myositis

Insurance coverage changing for families with chronically ill children

The Affordable Care Act has brought changes to the lives of families with sick children, and will bring more as mandates are phased in. Some major points of change are listed below:

No lifetime dollar limits on essential coverage

Job-based health plans and new individual plans are forbidden to deny or exclude coverage for your children (under age 19) based on a pre-existing condition, including disabilities.

Starting in 2014, these same plans won't be allowed to deny or exclude anyone of any age or charge more for a pre-existing condition, including a disability. Meanwhile, parents have new options for covering their children.

If your children are younger than 26, you can generally insure them if your policy allows for dependent coverage. The only exception is if you have an existing job-based plan, and your children can get their own jobbased coverage.

An "Affordable Insurance Exchange" is a new marketplace where individuals and small businesses can buy affordable health benefit plans. Exchanges will offer a choice of plans that meet certain benefits and cost standards. Starting in 2014, members of Congress will get their health care insurance through exchanges, and you will be able to buy your insurance through exchanges, too.

Vision and dental coverage for children will be covered in all exchange plans and new plans sold to individuals and small businesses, starting in 2014.

In 2014, if your income is less than about \$88,000 for a family of four, and your job doesn't offer affordable coverage, you may get tax credits to help pay for insurance.

Resources for coverage and low-cost care:

Children's Health Insurance Program (CHIP)

CHIP covers children whose families don't qualify for Medicaid but can't afford to buy health insurance.

Who qualifies for CHIP?

Every state operates a CHIP, although most states have unique names for their programs like Child Health Plus (New York), Healthy Families (California), and Hoosier Healthwise (Indiana). In several states, CHIP and Medicaid are combined into one program.

Basic eligibility for CHIP:

• Children up to age 19 in families with incomes up to \$45,000 per year (for a family of four) are likely to be eligible for coverage. In many states, children in families with higher incomes can also qualify.

• Citizenship and immigration status: CHIP covers U.S. citizens and certain legal immigrants. States have the option of covering children and pregnant women who are lawfully residing in the United States. Undocumented immigrants aren't eligible for CHIP.

What does CHIP cost?

Routine "well child" doctor visits are provided free of charge, but there may be co-payments for certain other services. Many states also charge a monthly premium for coverage. The costs you'll be responsible for under CHIP are different in each state, but cannot be more than 5% of your family's income each month.

What services does CHIP cover?

The benefits covered through CHIP are different in each state, but all states are required to cover these services:

- Routine check-ups
- Immunizations
- Dental and vision care

Inpatient and outpatient hospital care

Laboratory and X-ray services

To find information about children's coverage programs in your state and other options available to you, visit InsureKidsNow.gov or call 1-877-543-7669.

About InsureKidsNow.gov

InsureKidsNow.gov provides information about Medicaid and CHIP services for families who need health insurance coverage. These programs are designed to be affordable for families who are not able to afford health insurance coverage in the private market or do not have coverage available to them. Even if you've been turned down in the past, you may be able to get health coverage for your child now. Learn more about health coverage programs in your state by going to www.insurekidsnow.gov/programs.html, and typing in your zip code. If you do not have a computer, call 1-877-543-7669.

About Medicaid

The Medicaid program has been in operation since 1965, and the CHIP program was created in 1997. The Children's Health Insurance Program Reauthorization Act of 2009 (CHIPRA) allows states to have more opportunities to improve access to these programs.

How to contact Medicaid

If you have specific questions about health insurance for your children, call free of charge 1-877-543-7669, a confidential hotline, where you'll be connected directly to someone from your state who will help you apply.

New guidelines for IVIG

Recently, the American Academy of Neurology released guidelines attesting to the efficacy of intravenous immunoglobulin (IVIG) for neuromuscular disease, including dermatomyositis and polymyositis. Although similar guidelines have not been issued for children, many IViG patients are children and young adults with myositis. See the IVIG supplement in the preceding pages, which includes information about the manufacture, treatment and availability of IVIG for myositis patients. You'll also find information about home infusion and patient advocacy.

Keep children safe in the sun: understanding sun-protective clothing

If you've been trying to protect your child from the sun, you may find it a difficult project. Children want to play outdoors in summer and, if your child is feeling well at all, you want to encourage this. Since sunscreen is often unreliable as time elapses, more and more people now consider sun-protective clothing, which is growing in popularity. It is widely believed that exposure to sunlight may aggravate a flare in muscle inflammation as well as an increase in the rash of juvenile dermatomyositis.

Most outdoor clothing now carries a UPF rating, which may further confuse parents. What does a UPF rating mean? Is it realistic to expect a child to wear sun protection clothing?

What is UPF?

Ultraviolet Protection Factor (UPF) is a rating system used for apparel. It indicates how effectively fabrics shield skin from ultraviolet (UV) rays. The higher the UPF number, the greater degree of UV protection a garment offers.

UPF is similar to SPF, the rating system used for sunscreen products. UPF gauges a fabric's effectiveness against both ultraviolet A (UVA) and UVB light. An SPF number pertains only to a sunscreen's effectiveness against UVB rays, the sunburn-causing segment of the ultraviolet spectrum. Most sunscreens include ingredients that shield skin from UVA rays, but sunscreen makers have yet to agree on how to measure that protection.

What is it about sunlight that puts my child's skin at risk?

Sunlight includes invisible ultraviolet radiation (UV-R).

There are three types of UV rays:

■ UVA rays cause premature skin aging, wrinkling and skin cancer. They penetrate skin more deeply than UVB rays. They can affect skin during any hour of daylight and penetrate through clouds and glass. ■ UVB causes sunburn as well as premature skin aging and skin cancer, and is most damaging between 10am and 4pm. These rays penetrate clouds, but not glass.

• UVC rays are deadly to humans. Luckily, they never get to us. They are absorbed by atmospheric gases before they reach the earth's surface.

Excessive UV radiation weakens the body's immune system even in people who do not have an autoimmune disease.

Many dermatologists believe that clothing shields skin more effectively from UV light than does sunscreen, mostly because we don't apply sunscreen as thickly or as often as we should for sun protection.

Interpreting UPF ratings

UV-protection claims for clothing were developed in the 1990s in Australia, where skin cancer is a widespread concern. Researchers there developed the first fabric testing procedures for UV transmission and created a UPF rating system. Clothing manufacturers have since voluntarily adopted this system.

A UPF rating of 50 indicates the fabric of a garment will allow only 1/50th (roughly 2%) of available UV radiation to pass through it. A garment rated UPF 25 permits roughly 4% (1/25th) UV transmission. The higher the number, the better the protection the fabric offers. Any fabric that allows less than 2% UV transmission is simply labeled UPF 50+.

All fabrics in some way block UV radiation. A white cotton T-shirt, for example, might fall between UPF 5 and UPF 8, meaning that it could allow as much as 20 percent of available radiation to pass through. T-shirts that have been repeatedly washed in detergents with "brighteners" are actually more protective than new ones. And tests showed that good-quality sun-protective clothing kept or improved its sun-protective qualities through repeated washings.

Fabrics are said to "soak up" rays, but that's not exactly true. When UV radiation reaches fabric, the energy is changed. UV radiation is converted to heat, which makes it harmless. Some garments, depending on how they're made, and what dyes are used, do a better job at this than others.

The original Australian rating system stipulates that garments made with fabrics rated below UPF 15 cannot be marketed as UV-protective. In the U.S., the Federal Trade Commission monitors UPF advertising claims. Most manufacturers and retailers voluntarily follow one of more of the standards, testing methods and labeling guidelines.

Children, who sometimes find sunscreen unappealing and resist its use (or chronically forget to use it) may accept the use of UPF-rated clothing more readily. Although untreated clothing does form a barrier against the sun, a standard Tshirt is not always adequate for shielding the child from the effects of UV light.

It may not take as much getting used to as you imagine. If you consider the clothing worn by desert people, you can see that lightweight, loose-fitting, sun-shielding body coverings have been worn from head to toe for centuries. Today's modern fabrics, many of them moisture-wicking, quick-drying and highly breathable, make it possible and even comfortable for you to shield your child's skin from UV light while he or she plays outside.

Achoo! Hello sunshine

By Cari Nierenberg

Sometimes, a funny thing happens when Dr. Roberta Pagon looks directly into the sun. She sneezes. Not just once though, but usually three times.

She's not the only one in her family who sneezes when sunlight hits their face -- two of her children also react by sneezing three times in a row. And now a grandchild does it, but only sneezes once.

Odd coincidence? Not really, says Pagon, a pediatrician in the division of genetic medicine at Seattle Children's Hospital. This tendency to sneeze at sunlight is known as the "photic sneeze reflex," and it's hereditary.

Not only is there a genetic basis for "sun sneezing," Pagon says the number of times people sneeze in response to light also appears to run in families.

This scientific discovery happened in a very unscientific way.

Pagon and her genetics colleagues were sitting at the same table during a birth defects conference when the conversation shifted to discussing the sun and sneezing. Much to their surprise, they learned that 4 out of 10 of them were affected by this strange reaction. "One person said it was common for people in his family to sneeze five times; in my family it was three times, and another person said once," recalls Pagon.

They quickly did what years of medical training had taught them -- they coined an acronym for it: ACHOO syndrome, or Autosomal Dominant Compelling Helio-Ophthalmic Outburst.

Autosomal dominant stands for the way the 'sneeze gene' is inherited; an individual has a 50-50 chance of passing this trait on to a child. "Compelling" because it was well, interesting, or at the very least, quirky. "Helio" meant sun, "ophthalmic" meant eye, and "outburst" the end result. They even wrote up a paper about the peculiar phenomenon.

Although this reaction might seem unusual, it's not that uncommon. By one estimate, 18% to 35% of people get a tickling sensation in their nose when their eyes meet intense sunlight. Some folks may also get this weird response to bright artificial light, such as the eye doctor's or dentist's light or a photographer's flash.

Driving out of a tunnel may trigger the reflex or leaving a movie theatre on a summer's day, says Nicolas Langer, PhD, a neuropsychology researcher at the University of Zurich, who has studied the photic sneeze reflex. Often "it's just the change of a dark location to a bright (very sun exposed) location" that brings on the reflex, he explains.

In his research, Langer compared the visual reactions of 10 sun sneezers to 10 people without this reflex. Volunteers were hooked up to an EEG machine so the scientists could measure their brain and neural responses when exposed to bright light.

Their results suggest that "the 'photic sneeze reflex' is not a classical reflex that occurs only at a brainstem or spinal cord level," says Langer. "It seems to involve other cortical areas" of the brain.

As for why it happens, Langer offers two theories. One is that the visual system in the brain is more sensitive in photic sneezers.

A second possibility is that two nerves (the optic nerve and trigeminal nerve) are too close together in photic sneezers. Langer says light may cause stimulation of the optic nerve in the eye, which then coactivates the trigeminal nerve in the face, and results in an achoo reaction.

Solar sneezes could be an occupational hazard if you're an airplane pilot, baseball outfielder, sky diver, puntreturn specialist, or high-wire acrobat. But for roughly one of out four people, it's merely something curious that makes them a little different from the next guy or gal. 3



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